

**UGANDA ASSOCIATION FOR THE MENTALLY HANDICAPPED/INCLUSION
UGANDA**

ANNUAL REPORT 2021

1.INTRODUCTION

1.1 About Uganda Association for the Mentally Handicapped/Inclusion

Inclusion Uganda is a non-governmental organization that works with people with intellectual disabilities and their families. Inclusion Uganda was established in 1983 by a group of parents and professionals of children with disabilities who came together to find a common solution to the problems that were affecting their children both at home and in their communities.

Inclusion Uganda believes that people with intellectual disabilities have the ability, will, and creativity to impact their societies given the right support and information.

1.2 Vision statement

A society where the rights of people with intellectual disabilities are observed, protected and promoted.

1.3 Mission statement

Our mission is to advocate for the rights of people with intellectual disabilities through public awareness, civic leadership, engagement and community participation.

1.4 Our core values

- Inclusion of people with intellectual disabilities in all sectors.
- Equality and respect of people.

1.5 Why people with intellectual disabilities

Intellectual disability is one of the most marginalized type of disability in Uganda. People with intellectual disability are segregated against by people with other disabilities due to the fact that they have slower mental progression. According to our interactions with different personnel at grass root level, people with intellectual disability are not even included in government programs. This is also attributed to the negative attitudes of parents and community members towards intellectual disability. However, interventions from both government and civil society organizations have aided to reduce this gap although there is still need for further interventions especially in rural areas.

2. EXECUTIVE SUMMARY

Uganda Association for the Mentally Handicapped/Inclusion Uganda is a key contributor to advocacy of the rights of people living with intellectual disabilities in Uganda. We cultivate a bottom-up approach focusing on attitude change amongst people living with intellectual disabilities, their families and communities as well as a systematic change in policies and regulations geared towards a more inclusive environment for people with disabilities at large.

We leverage local and foreign grants to deliver programs in support and promotion of the welfare and rights of people living with intellectual disabilities with reference to the CRPD.

We delivered programs to eight districts in Uganda namely; Kampala, Wakiso, Luwero, Lwengo, Bukomansimbi, Mukono, Kibuku and Tororo under Human Rights advocacy, Economic empowerment, Families taking action and Community Based Rehabilitation. Our primary objectives for 2021 were to continuously improve the competence of advocacy through trainings and capacity building, using the CRPD as a tool for domestic change and strengthening the socio-economic empowerment of people with intellectual disabilities and their families.

We accomplished these through advocacy trainings for people living with intellectual disabilities, local leaders and parents, Community Based Rehabilitation and parent self-help groups formed to foster socio-economic welfare through families taking action.

Innovations and partnerships are still very critical to attaining the CRPD and SDGs and to our role as a Disability Peoples Organization. Over the past year, we realized new partnership opportunities with civil society organizations with in the TOFI consortium, Greater Masaka Cerebral Palsy Association and Local Governments at district and sub county levels to better position efforts to address the various challenges people with intellectual disabilities are facing. This also prompted Local Governments to enact by-laws that aim at protecting marginalized groups in their communities.

3. OBJECTIVES

Our objectives for 2021 included the following;

- i. To promote the wellbeing and conditions of people with intellectual disabilities and their families in Uganda.
- ii. To enlighten the public, policy makers, administrators, professionals and government officials about the problems, needs, and rights of people with intellectual disabilities.
- iii. To coordinate efforts of parents, government officials and professionals in providing and rendering service to the people with intellectual disabilities and their families in Uganda.
- iv. To mobilize parents and communities for action.

4. OUTPUTS

Our target output/impact included the following;

- i. 450 support persons/parents trained on advocacy for the rights of people with intellectual disabilities using the CRPD as a domestic tool.
- ii. 450 local leaders trained on advocacy for the rights of people with intellectual disability and their responsibility towards upholding and protecting their rights.

- iii. 120 persons with intellectual disabilities trained on the CRPD and self – advocacy
- iv. 75 families receive community-based rehabilitation in Lwengo, Kibuku and Luwero districts.
- v. A fully constructed consultation center in Kagumu, Kibuku district.
- vi. 35 parent self-help groups formed to foster socio-economic welfare of families of people with intellectual disabilities.

5. KEY ACTIVITIES

We had the following activities for implementation during 2021.

- Trainings on the Convention on the Rights of People with Disabilities for support persons/parents, local leaders and people with intellectual disabilities.
- Community Based rehabilitation interventions in Kibuku, Lwengo and Luwero districts.
- Construction of a consultation center in Kibuku district
- Capacity building of Inclusion Uganda staff for better service delivery
- National and regional meetings for local executive committee representatives to share experiences and resources.
- Meetings with ministries, departments and agencies working on advocacy for Human Rights.
- Parent self-help groups formed to foster socio-economic welfare through families taking action.
- Awareness raising of the rights of people with intellectual disabilities through national celebrations.

6. IMPLEMENTATION FRAMEWORK

6.1 Human Rights Advocacy trainings

6.1.1 Training of parents, caretakers and siblings of persons with intellectual disabilities on the CRPD and intellectual disability.

During these trainings, we leveraged on the Community Development Officers and field volunteers to mobilize for participants and service providers.

We had trainings of 25 participants of parents per training for one day in each sub county totaling to 3 trainings per district. A total of 409 parents were trained of these 106 males (14 with disabilities) and 303 females (7 with disabilities).

We also hired consultants to deliver information on the CRPD with emphasis on Articles 12 and 27. We carried out these trainings in 3 sub counties in 6 districts in Uganda namely;

- a) Bukomansimbi district – Kitanda, Kibinge and Bigasa sub counties
- b) Lwengo district – Kyazanga, Kisekka and Ndagwe sub counties
- c) Mukono district – Nama, Kyampisi and Nakifuma-Nagalama sub counties.
- d) Luwero district – Makulubita, Bombo and Nyimbwa sub counties

- e) Kibuku district – Kagumu, Kadama and Bulangira sub counties
- f) Tororo district – Merikit, Osukuru and Nagongera sub counties.

These trainings were dominated by females (mothers and grandmothers) as most of them are the sole caretakers of persons with intellectual disabilities in their families. We therefore realized that there is still a gap as we need to bring the fathers on board as well. Most mothers allege that fathers completely turned the responsibility of caring for children with intellectual disabilities as they consider them to be losses to the family. A parent in Kyampisi shared that her husband told her that “in his lineage, they don’t have any one with Down syndrome and thus abandoned his son”.

It is such beliefs and mindsets that Inclusion Uganda is fighting to address through these advocacy trainings. We therefore believe that with more trainings especially in the rural areas, we will be able to attain communities where the rights of people with intellectual disabilities are respected.



Parents attending a training in Nakifuuma-Nagalama town council main hall in Mukono district.



Parents in Osukuru sub county engaging in a group discussion during one of our trainings.

6.1.2 Training of local leaders, opinion leaders and Village Health teams on the CRPD and intellectual disability.

These trainings were aimed at reminding the local leaders of their roles in protecting and preserving the rights of people with intellectual disabilities. We had 25 participants per training in each of the three sub counties in six districts in Uganda. We held these trainings concurrently with trainings of parents for two consecutive days in every sub county. We usually had parents coming on day one and local leaders on day two.

A total of 447 adults were trained of these 280 males (43 with disabilities) and 167 females (22 with disabilities).

As a result, the local leaders were empowered to take on the advocacy role within their communities so that persons with disabilities are involved and equally represented in all local governance committees.

We had more males than females in these trainings because we believe that men occupy most leadership positions in communities.



Local leaders in Nakifuma-Nagalama participating during one of our trainings.



Bangi Toubah, a social worker and teacher taking local leaders in Mukono through Article 12 of the CRPD.

6.1.3 Training of persons with intellectual disability on the CRPD.

89 persons with intellectual disabilities were trained on the CRPD, of these 40 males (23 adults, 17 children) and 49 females (28 adults, 21 children). The participants were able to learn that they also have equal recognition before the law and also have a right to work and employment. As a result of these trainings, the self-advocates will be able to start advocating for their rights before the law, at home, in their communities and in their workplaces.



A person with intellectual disability interacting with her support person during a training in Kyazanga sub county, Lwengo district.



A person with intellectual disability sharing his view during a training in Kitanda sub county, Bukomansimbi district.

6.1.4 Advocacy trainings for persons with Down syndrome.

An advocacy group with 10 persons with Down Syndrome was formed to advocate for their rights and the rights of others. This group underwent several trainings on the CRPD with emphasis on work and employment - Article 27 of the CRPD. As a result of these trainings, these

self-advocates have been able to negotiate for better working conditions at their work places. A case in point is Wafula Ian who was not paid promptly like other employees at his work place because he has Down syndrome, however as a result of these trainings together with other members in their advocacy group, they visited the garage where Ian works and advocated for inclusive employment for Ian. We can boldly testify right now that Ian is paid promptly and fully supported by all employees in the garage.



Some of the members in our advocacy group



A person with Down syndrome at his work place.

6.2 Community Based Development

6.2.1 Rehabilitation

Community meetings were held at the inception the project in the different project areas namely;

Kisekka sub county in Lwengo district

Kagumu sub county in Kibuku district

Makulubita sub county in Luwero district.

These meetings involved Local Committee Executive members, local leaders, volunteers and field workers. The volunteers and field workers were divided into groups and discussions were held about each group's role and expectations.

People with intellectual disabilities were assessed and given the necessary rehabilitation. 26 children and adults received wheel chairs, 12 children received bucket toilets and therapeutic tables, parallel bars were installed in 28 homes and as result 17 persons who were unable to walk before started walking with support. Over 30 families received beddings and clothes for persons with intellectual disabilities.



Persons with disabilities from Kagumu sub county, Kibuku district receiving wheel chairs.

6.2 Parent self-help groups formed to foster socio-economic welfare through families taking action.

Self help groups were established in 3 project areas. A total of 30 groups were established and bank accounts were opened up in each area. The groups started enterprises in agriculture and trading in local merchandise.

The following rules/ modalities were made;

- Each group had a chairperson, secretary and treasurer.
- Each group opened up books of accounts to record both cash inflow and outflow.
- The profits were kept on the accounts until 6 months to begin with.
- 20% of the profits were added to the initial capital so as to build a bigger capital base for the enterprise.
- Members of the group shall share 80% of the profits after 6 months to begin with.



A group dealing in selling crafts in Kisekka sub county, Lwengo district.



A group dealing in fish farming in Makulubita sub county, Luwero district.

6.3 Construction of a consultation center in Kagumu sub county, Kibuku district.

A technical company was hired to carry out construction of the center. The main objective of constructing this center was to work as a consultation center in the areas of disability health, rights, counselling and information given the alarming rate of persons with disabilities in Kagumu sub county.



6.5 Capacity building of board and staff members for better service delivery.

21 persons were trained on project management, team building and supportive supervision. This was a two days training aimed at improving the efficiency of board members and productivity of the staff. We hired two consultants to cover the selected topics. The training took place at our office premises in Bwaise.



Staff members attending a training on capacity building.

6.4 National and regional meetings for local executive committee representatives to share experiences and resources.

18 persons with intellectual disabilities and 18 representatives from three different regions i.e. Central, Eastern and Greater Masaka met to share experiences and also learn from one another. People with intellectual disabilities and local committee representatives were

educated on advocacy and human rights. these meetings were held for one day in hotels in the respective regions.



One of the participants sharing experience during a meeting at Tick hotel in Kampala



A participant taking others through an energizer at a meeting held at Maple leaf hotel, Masaka district.

6.6 Awareness raising of the rights of people with intellectual disabilities through national celebrations.

We raised awareness on cerebral palsy during the World Cerebral palsy day celebrations. We held talk shows and also conducted mass media drives through out Greater Masaka. We also partnered with organizations like Greater Masaka Cerebral Palsy Association and United Persons with Cerebral Palsy, Nyendo during the main event at Maple Leaf Hotel, Masaka district.



A group of persons with cerebral palsy pose for a picture together with their parents.

7. Achievements

We registered the following achievements in 2021

- 89 persons with intellectual disabilities were trained on the CRPD, of these 40 males (23 adults, 17 children) and 49 females (28 adults, 21 children). The participants were able to learn that they also have equal recognition before the law and also have a right to work and employment. As a result, the self advocates were able to start advocating for their rights before the law and in their workplaces.
- 447 local leaders were trained on the CRPD, of these 280 males (43 with disabilities) and 167 females (22 with disabilities). This training was aimed at reminding the local leaders of their roles in protecting and preserving the rights of people with intellectual disabilities. As a result, the local leaders were empowered to take on the advocacy role within their communities so that persons with disabilities are involved and equally represented in all local governance committees.
- We held regional meetings for parents and persons with intellectual disabilities to share experiences. 20 persons with intellectual disabilities (10 males, 10 females) met with 16 parents (7 males, 9 females) to learn from each other and also be reminded of their role towards advocating for their rights. We identified 12 self-advocates that we shall take on as TOTs in 2022.

- 19 board members and staff of Inclusion Uganda (7 males, 12 females) were trained on organizational management and operations with emphasis on project management, team building, strengthening capacity, risk management and supportive supervision.
- We raised awareness on cerebral palsy during the World Cerebral palsy day celebrations. We held talk shows and also conducted mass media drives through out Greater Masaka. We also partnered with organizations like Greater Masaka Cerebral Palsy Association and United Persons with Cerebral Palsy, Nyendo.
- 31 Self help groups were established in three project areas i.e Kisekka sub county in Lwengo district, Makulubita sub county in Luwero district and Kagumu sub county in Kibuku district. These groups uplifted the general social and economic well being of people with disabilities and their families.
- A consultation center was constructed in Kagumu sub county, Kibuku district. This consultation center provides information and services in the areas of disability health, rights, counselling and information given the alarming rate of persons with disabilities in Kagumu sub county.
- A self-advocacy group of persons with Downs Syndrome was formed and empowered to advocate for their rights and the rights of others. This group is made up of ten self-advocates from Kampala, Wakiso and Mukono districts.
- We were also able to establish working relations with the Ministries of health, Education and Gender, Labor and social development as we continue to advance the inclusion of persons with intellectual disabilities.

8. Challenges/problems encountered.

- The emergence of the second wave of Covid 19 resulted into a lockdown which halted all our activities. As a result, some activities like “Breakfast Dialogue on the impact of Covid 19 on the lives of people with intellectual disabilities” was postponed to 2022.
- We also further reduced the number of participants of our trainings from twenty-five to twenty as per the government guidelines. Our activities were further delayed by some district Covid 19 task forces that delayed to permit our activities after lifting of the lockdown. We ended up spending longer training periods in order to be able to cover our target population.
- Difficult political environment as we have had most of our trainings in the post-election process.
- Resistance from some parents since most of them think in terms of material gains. Some parents denied us access to their homes to conduct Community based rehabilitation on their children because they felt like they weren’t direct beneficiaries.

- Limited participation of fathers during our programs. We realized that most of our activities are dominated by mothers and grandmothers of people with intellectual disabilities.
- Some self-help groups lost their investments and as result the intended purpose was not achieved.

9. Lessons learnt

- While drawing workplans, we need to bear in mind the possibility of natural and political disasters.
- There is need for continuous awareness campaigns to further sensitize communities on the rights of people with intellectual disabilities and programs put in place by government to improve the welfare of persons with disabilities.
- Involvement of local leaders and opinion leaders in our trainings and as result there is increased awareness on the rights and inclusion of people with intellectual disabilities in community activities.
- Engagement of district and sub county technical personnel in our trainings for example CDOs, Probation officers, VHTs. This encourages continuity of our programs and follow up. This also makes mobilization of participants easier.
- Very few fathers are involved in the lives of their children hence there is need for more sensitization to fathers of persons with intellectual disabilities.

10. Conclusion

Inclusion Uganda envisions a society where the rights of people living with intellectual disabilities are observed, protected and promoted. We have learnt that advocacy requires consistent and continuous engagements with all stakeholders from the grass roots to the top leadership. We also continue to monitor and improve output with focus on Monitoring, Evaluation and Learning.

However, we still faced overwhelming numbers of people living with intellectual disabilities unattended to due to limited resources. This was further exacerbated by the COVID 19 pandemic which led to early marriages and pregnancies amongst children with intellectual disabilities, inaccessibility to medical facilities, domestic violence and restrictions as we had to cut down on the number of participants. There is still a gap in creating awareness on the rights

of people living with intellectual disabilities especially in deep rural areas where cultural beliefs are still linked to intellectual disability hence there is need for more sensitization/ trainings to reach out to more families and people living with intellectual disabilities. We call upon the government of Uganda to partner with Civil Society Organisations to ensure that the laws put in place to protect the rights of persons with disabilities are fully enforced and upheld by all citizens.